

# Adult Carers: Factsheet

## Tower Hamlets Joint Strategic Needs Assessment 2010-2011

### Executive Summary

A higher proportion of the Tower Hamlets population (1.32%) provides 20 -49 hours unpaid care per week to a family member, partner or friend than the London (1.01%) or England average (1.08%). The proportion providing 50 hours or more per week in Tower Hamlets is the highest in London (2.38% in Tower Hamlets compared to 1.66% in London and 2.03% in England). Nationally, carers have worse general health than the general population. In Tower Hamlets carers have worse general health than the national carers' average.

The Carers Strategy Implementation Group is a multi agency group that oversees implementation of the Carers Strategy in Tower Hamlets. Current priorities of the group include:

- Development of marketing plan to increase awareness of the support available to carers in Tower Hamlets, leading to greater uptake of services.
- Increased provision of training related to carers' assessments, including promotion of annual health checks.
- Commissioning of Dementia Advisor service as part of the Dementia Awareness Raising Strategy.
- Protocol for carer support during transition period of the person they care for (ages 15-25).
- Monitoring the completeness of Carers Registers in Primary Care through quarterly reports by GP Practices.
- Review of current breaks available for carers, with a view to increasing flexibility and use of carer one off direct payments.
- The interests of carers to be included in the updated Reablement Service Operational Policy.
- Partnership working with Job Centre Plus and Carers Centre to engage carers re Employment training programmes.

### 1. What is a carer?

A carer is defined as someone who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems<sup>1</sup>.

Within this group there is substantial variability. The carer-cared for relationship can be adult to adult, parent to child (young or adult) or young carers caring for others. Those cared for might be relatives, friends, or neighbours. The reasons someone might require care include frailty (older people), learning disabilities, physical disabilities, serious illness, mental health conditions, and substance abuse, or a combination of reasons. This variability results in complex and diverse carer needs. Some of the types of support that someone might need from a carer include:

- Moving around the house
- Washing and dressing
- Eating and preparing meals
- Shopping for groceries
- Making telephone calls or filling in forms
- Managing money, such as paying bills
- Taking medicines
- Attending appointments
- Work around the house or garden

<sup>1</sup> Department of Health (2008) Carers at the heart of 21<sup>st</sup> Century families and communities: "A caring system on your side. A life of your own".

- Having someone to talk to

Some people may need 24 hour care and cannot be left alone; others may require a daily reminder to take medicine, and a weekly food shop; others might be very independent, but need emotional support during times of crisis.

It is also important to consider the exacerbation of difficulties faced by carers for those who are engaged in complex multiple caring roles, caring for more than one person or caring for people with more than one condition or need.

Nationally, approximately **one in ten people is a carer**<sup>2</sup>. The number of people taking on a caring role is rising all the time, as more people live longer or develop long term conditions, and simultaneously aspire to maintain independence and control over their lives. The caring relationship is most frequently established within the family, often creating complex interdependencies across generations.

“It is estimated that there are more than 6 million adult carers in the UK providing unpaid care to the value of £87 billion. In 2006-7 the total cost of the entire National Health Service was £82 billion. Total spending on Social Services in 2005-6 was £19.3 billion thus demonstrating the huge contribution that unpaid carers contribute to the social care system of the UK”<sup>3</sup>.

## 2. What is the local picture?

There are around 21,000 unpaid carers in Tower Hamlets in 2010, of whom at least 5,800 provide 50 hours or more of unpaid care per week. A higher proportion of the Tower Hamlets population (1.32%) provides 20 -49 hours unpaid care per week to a family member, partner or friend than the London (1.01%) or England average (1.08%). The proportion providing 50 hours or more per week in Tower Hamlets is the highest in London (2.38% in Tower Hamlets compared to 1.66% in London and 2.03% in England)<sup>4</sup>.

- 63% of carers (providing 20 hours or more unpaid care per week) in Tower Hamlets are female.
- 18% of carers are of pensionable age.
- 3% of carers are under the age of 16.
- 44% of carers are Bangladeshi<sup>5</sup>.
- 41% are white British.

The gender discrepancy is largest in the working age group, where 64% of carers are female. In the younger carer group 52% are female.

In the young carer group 64% of carers are Bangladeshi (almost 80% for female young carers) and just 18% white British. This varies across older age groups; 49% of working age carers are Bangladeshi and less than 16% of older carers are Bangladeshi. The Asian population is disproportionately represented as carers (compared to the general Tower Hamlets population) in the working age group in particular.

A survey of carers in Tower Hamlets found that health problems are commonly reported. Around two thirds of carers surveyed reported experiencing tiredness or disturbed sleep. Around one third of carers reported feelings of stress, depression and physical strain<sup>6</sup>. Carers in Tower Hamlets have worse general health than carers

<sup>2</sup> National Statistics (based on 2001 Census).

<sup>3</sup> Valuing Care, Carers UK & University of Leeds, 2007- from [www.carerscentretowerhamlets.org.uk](http://www.carerscentretowerhamlets.org.uk).

<sup>4</sup> 2001 Census percentages applied to current GLA population estimates.

<sup>5</sup> This is based on 2001 Census data and may have changed substantially since then.

<sup>6</sup> Tower Hamlets Carers Survey, NHS Information Centre, 2010.

surveyed nationally and than the general Tower Hamlets population. Forty one percent of carers surveyed reported their general health to be good or very good (49% England average<sup>7</sup>), compared to 77% of the Tower Hamlets population as a whole<sup>8</sup>.

Carers in Tower Hamlets experience more financial difficulties as a result of caring than the national average. Fifty one percent of carers surveyed in Tower Hamlets reported some or a lot of financial difficulties, compared to 40% surveyed in England as a whole.

Seventeen percent of carers surveyed in Tower Hamlets reported their quality of life to be 'bad or worse', which is similar to the national average for carers. Eighteen percent of carers in Tower Hamlets reported not having time to do 'anything they value or enjoy' compared to 13% nationally.

Around 7% of carers surveyed look after more than one person, both in Tower Hamlets and nationally. However, carers in Tower Hamlets are more likely to live with the person they care for (84% in Tower Hamlets, compared to 73% England average). This is likely to result in a more time intensive caring role, which may explain the higher than average proportion of the Tower Hamlets population providing 20 hours or more care per week. Fifty one percent of carers surveyed in Tower Hamlets reported spending 100 hours or more per week caring, compared to 37% of carers nationally.

Carers in Tower Hamlets report feeling less supported by services than average. Only 76% of carers in Tower Hamlets report feeling 'always or usually' supported by their GP, compared to 81% nationally. Seventy five percent of carers in Tower Hamlets report feeling 'always or usually' involved in hospital discussions about the person they care for, compared to 82% nationally.

### 3. What are the effective interventions?

The national carers' strategy, [Carers at the heart of 21<sup>st</sup> Century Families and Communities \(2008\)](#)<sup>9</sup> was refreshed in 2010. [Recognised, Valued and Supported: next steps for the Carers' Strategy](#)<sup>10</sup> identifies six key priorities for supporting carers:

#### **Identification and Recognition**

Carers should be encouraged to identify themselves as carers at an early stage, facilitating access to information and advice. In November 2010, the Department of Health awarded almost £2 million in grants to Carers UK, Crossroads Care, The Princess Royal Trust for Carers, Partners in Policymaking, The Afiya Trust and The Children's Society to support their work with carers. In addition, it has launched the [Reaching out to Carers Innovation Fund](#) to encourage patient-led and condition-specific voluntary organisations to focus more on how they can support carers.

Health and social care professionals must recognise the value of carers' contributions and must involve them in the design of local services as well as in planning individual care packages. Carers should be routinely involved in the Joint Strategic Needs Assessment.

#### **Realising and Releasing Potential**

Young and adult carers should be enabled to fulfill their educational potential. Aspirations for education,

<sup>7</sup> 2009-10 Personal Social Services User Experience Survey of Carers. Copyright © 2010, The Health and Social Care Information Centre. All Rights Reserved.

<sup>8</sup> Tower Hamlets Carers Survey, NHS Information Centre, 2010 and Tower Hamlets Health and Lifestyle Survey, 2010.

<sup>9</sup> Department of Health (2008) Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own.

<sup>10</sup> Department of Health (2010) Recognised, valued and supported: next steps for the Carers Strategy.

training, work and leisure should be taken into account when assessing a carer's needs. Carers should also be enabled to fulfill their employment potential, which requires employers and colleagues to be understanding and flexible.

### ***A life outside of Caring***

Carers should be enabled to have a family and community life though personalized support for both themselves and the people they care for. No assumptions should be made about a carer's ability and willingness to care. As outlined in the [Vision for Adult Social Care](#), personal budgets will be the norm, but carers should not have to manage financial arrangements or procure their own services unless they wish to – an anxiety particularly among older carers. ADASS and the Princess Royal trust for Carers have developed a carers support pathway and a self assessment audit tool: [Commissioning better outcomes for carers – and knowing if you have.](#)

### ***Supporting Carers to stay Healthy***

Studies show that people providing high levels of care are twice as likely to have poor health as those without caring responsibilities. Supporting carers is a key element of the prevention and public health agendas, as evidenced in the Public Health White Paper [Healthy Lives, Healthy People \(2010\)](#). Breaks are extremely important for maintaining good health, but mainstream provision tends to be still one-size-fits-all; the majority of carers who have experienced a good break have organised this themselves through direct payments.

### ***Developing an Evidence base for Supporting Carers***

Further evidence is required on the impact and effectiveness of carer specific services and interventions, in terms of outcomes such as carers being informed, having a break, accessing emotional support, maintaining their own health, and having a voice.

### ***Supporting Local Delivery, Transparency and Local Accountability***

Carers should be involved and able to contribute their knowledge and expertise to the Joint Strategic Needs Assessment (JSNA) and service planning. "Co-production with carers should be integral to the delivery of all care services"<sup>11</sup>.

[The Carers Equal Opportunities Act \(2004\)](#) places a duty on social services departments to inform carers of their right to an assessment. The purpose of the assessment is to determine what types of support a carer may need to continue providing care, but should also include a discussion on any effects caring is having on the carer's health, relationships, ability to go out, as well as whether the person they care for is receiving enough support, whether the carer wishes to start paid work or continue to work, their wish for further education and their wish to engage in leisure pursuits.

## **4. What is being done locally to address this issue?**

Approximately 9% of all people identifying themselves as a carer in Tower Hamlets (1,870 carers) received an assessment or review in 2009/10 (100 per 10,000 adult population; figures are not available for London, but were 75 per 10,000 population in London in 2008/09). The majority of these carers were aged 18-64 years, with 170 people aged 75 and over receiving carers' assessments or reviews. Fifty four percent of carers assessed in 2009/10 were caring for someone aged 65 or over, the majority of whom had either a physical disability or mental health condition. Most people who were caring for someone aged 18-64 were caring for someone with a mental health condition or physical disability, with a substantial minority having a learning disability.

One off direct payments for carers are available for people to spend in the way that is most useful for their individual situations. The majority of one off direct payments in Tower Hamlets are spent on washing machines, short breaks, computers, kitchen appliances, beds, home improvements and cars/ driving lessons.

<sup>11</sup> Cross Government Publication (2010) Recognised, Valued and Supported: next steps for the Carers' Strategy, p.35.

[Carers' Allowance](#) is available to those over the age of 16 who provide 35 hours or more care per week for someone who receives Attendance Allowance, Disability Living Allowance, or Constant Attendance Allowance. Those carers in full time education or earning over £100 per week are not entitled to the benefit. The amount received is not adjusted to take into account multiple caring responsibilities (i.e. caring for more than one person). Almost 3,000 people in Tower Hamlets receive Carers' Allowance<sup>12</sup>. It is not possible to estimate the number of people eligible who are not claiming Carers' Allowance.

A list of support services currently commissioned by London Borough of Tower Hamlets and NHS Tower Hamlets can be found at the end of this factsheet. It is planned to review services during 2011/12.

## 5. What evidence is there that we are making a difference?

The number of carers receiving carers' assessments or reviews in Tower Hamlets has increased from 945 in 2006/07 to 1,870 in 2009/10. As a rate, this represents an increase from 55 assessments or reviews per 10,000 adult population to 100 assessments or reviews per 10,000 adult population in 2009/10. This compares favourably to the London average of 75 assessments or reviews per 10,000 adult population (in 2008/09).

## 6. What is the perspective of the public on support available to them?

From forums or focus groups at the Carers Centre, St Hilda's and Alzheimer's Society, as well as a user experience survey sent to carers who received assessments or reviews in the past 12 months, the following issues were identified as important to carers locally:

- Respite (especially at the weekend when there is no day services provision)
- Time
- Awareness of services
- Respect
- Financial difficulties
- Control
- Social isolation
- Health issues (including stress)

Carers in Tower Hamlets highlight feeling a lack of respect shown towards them by services, demonstrated by the huge financial discrepancy between what professionals are paid to provide sitting services for the cared for, and the money carers receive for providing the same or greater level of care. Carers receive the equivalent of £1.50 per hour from Carers Allowance (£53.10 per week). They feel that this does not adequately reflect the extremely difficult job they do ('Undervalued, Underpaid, Overworked'), or the fact that they save the government a lot of money.

It is felt that the money professionals are paid to provide sitting services would be more effectively spent if flexibility was allowed to enable friends and family (other than the primary carer) to provide paid respite. This would allow minimum disruption for the cared-for, good continuity and trust in the quality of care provided, thus minimising the stress involved for the carer.

Carers often report being unaware of what respite services are available in the borough. Amongst those who do know of services, it is felt that there are not enough respite services, especially at the weekend when the person they care for does not attend school or day services<sup>13</sup>.

Carers sometimes find the aftermath of respite chaotic and struggle to regain the previous routine for the person

<sup>12</sup> <https://www.nomisweb.co.uk>, 2009/10.

<sup>13</sup> St Hilda's Carer Focus Group November 2009.

they care for. Anecdotally there is widespread demand for home based respite in which the individual is able to remain in familiar surroundings.

*"I spent a week away and came back to so many issues, had to spend at least six weeks to resettle my dad in again, he was confused and short tempered"<sup>14</sup>.*

The issue of time is central to carers' concerns: a lot of the time carers are invited to attend meetings, forums, user groups etc, and even if they want to go they are not able to because of time constraints<sup>15</sup>.

Carers frequently report experiencing difficulty preparing for the transition of the person they care for from children's to adults' services. It is essential that the carer is adequately involved in the care planning for the person they care for, as specified in national guidance<sup>16</sup>.

The Carers Centre was described as invaluable and having saved a lot of carers from 'going under', and carers feel that the Centre should be advertised more.

*"If you don't know about what's available, it's impossible to find out. No-one is putting information out there. It feels like a secret society. The services should advertise themselves more"<sup>17</sup>.*

## **7. What more do we need to know?**

GPs should hold more accurate registers of carers at each practice to enable better geographical targeting of services and information according to where carers live within the borough. This would also allow comparison of the health status of carers with the non-carer population, to evidence the effect of the caring role on health and wellbeing.

The 2011 Census should provide up to date data on the number of people providing unpaid care, the weekly hours they provide, and their characteristics. This information is unlikely to be available before 2013.

## **8. What are the priorities for improvement over the next 5 years?**

Priorities highlighted in the 2010/11 work plan of the Carers' Strategy Implementation Group include:

- Development of marketing plan to increase awareness of the support available to carers in Tower Hamlets, leading to greater uptake of services.
- Increased provision of training related to carers' assessments, including promotion of annual health checks.
- Commissioning of Dementia Advisor service as part of the Dementia Awareness Raising Strategy.
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- The interests of carers to be included in the updated Reablement Service Operational Policy.
- Partnership working with Job Centre Plus and Carers Centre to engage carers re Employment training programmes.

<sup>14</sup> Carer of someone with dementia, Tower Hamlets. From Bari, R. (2010) 'Service User and Carer Views on Dementia Services.

<sup>15</sup> Carers Centre Forum October 2009.

<sup>16</sup> Department of Health (2010) Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care.

<sup>17</sup> Comment from Tower Hamlets Carer User Experience Survey 2010.

## 9. Key Contacts & Links to Further Information

The general contact email for JSNA queries is [JSNA@towerhamlets.gov.uk](mailto:JSNA@towerhamlets.gov.uk)

Penny Collier is the Commissioning Manager for Carers, London Borough of Tower Hamlets,  
[penny.collier@towerhamlets.gov.uk](mailto:penny.collier@towerhamlets.gov.uk)

### Local Services:

**Tower Hamlets Carers Centre (Princess Royal Trust)** | 21 Brayford Square, Off Commercial Road, Stepney Green E1 0SG | Tel. 0207 790 1765 | [www.carerscentretowerhamlets.org.uk](http://www.carerscentretowerhamlets.org.uk)

**Alzheimer's Society** Tower Hamlets (for carers of people with dementia and memory problems) | Tel: 0207 392 9631 | [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

**Family Welfare Association** (for support to families of people with mental health conditions) | 22-28 Underwood Rd, E1 5AW | Tel: 0207 364 3406

**Age Concern** (for carers of older people) | 82 Russia Lane, E2 9LU | Tel: 0208 981 7124 | [www.acth.org.uk](http://www.acth.org.uk)

**APASENTH Care Services** (for Asian families caring for someone with a learning disability) | The Brady Centre, 192-6 Hanbury St, E1 5HU | [www.apasenth.org.uk](http://www.apasenth.org.uk)

**St Hilda's East Community Centre** | 18 Club Row, E2 7EY | Tel: 0207 739 8066 | [www.sthildas.org.uk](http://www.sthildas.org.uk)

**Black Women's Health and Family Support** (support for Somalian carers) | 82 Russia Lane, E2 | Tel: 0208 980 3503 | Email: [bwhafs@btconnect.com](mailto:bwhafs@btconnect.com)

**Jewish Care** | Tel: 0208 922 2222 | [www.jewishcare.org](http://www.jewishcare.org)

**London Buddhist Centre** | 51 Roman Road, Bethnal Green, London, E2 0HU | Tel: 0845 458 4716

**TLC Care Services** | 3rd Floor, 77 East Road, London, N1 6AH | Tel:020 7017 2836 | Fax:020 7017 2837 | Email: [towerhamletsrespite@tlccare.org.uk](mailto:towerhamletsrespite@tlccare.org.uk) | [www.tlccare.org.uk](http://www.tlccare.org.uk)

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<b>Date signed off by Senior JSNA Leads:</b>	08/04/11	<b>Signed off by (Public Health Lead):</b>	Somen Banerjee	<b>Date signed off by Strategic Group:</b>		<b>Sign off by Strategic Group:</b>	Carers Strategy Implementation Group
		<b>Signed off by (LBTH Lead):</b>	Deborah Cohen				